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Change in supportive care needs over the early disease trajectory for adults with primary brain tumours: a population-based study

Danette Langbecker and Patsy Yates

Background:

Primary brain tumours are rare among adults, but patients often experience physical, cognitive, neurological and psychosocial morbidity. Research has documented high rates of unmet supportive care needs among subgroups, such as patients receiving specific treatments or those receiving palliative care, but the needs of patients in the period soon after diagnosis are not known.

Aim:

To describe the unmet supportive care needs of adults recently diagnosed with primary brain tumours and change in needs over the early diagnosis/treatment period.

Methods:

A representative population-based sample of 40 patients was recruited approximately three months after diagnosis through a state cancer registry in Queensland, Australia. Patients or carer proxies completed surveys of supportive care needs in six domains (physical/daily living, psychological, patient care and support, sexuality, health system and information needs, and brain tumour-specific needs) at baseline and three months later. Mean supportive care needs scores (scale 0-100, with higher scores indicating higher levels of need) were calculated and compared over time.

Results:

The highest mean supportive care needs score at each time point was for physical needs (baseline 47.9, SD 26.3), closely followed by psychological needs (baseline 45.8, SD 35.6). Mean scores for other domains ranged from 30.4 to 37.9. Mean scores in all domains except for sexuality significantly declined over time, with the greatest decline for the patient care and support needs domain (mean 15.9 point decrease).

Conclusions:

Adults with primary brain tumours experience high levels of unmet physical and psychological needs early in the disease trajectory. However, levels of needs, particularly for patient care, decline over time, perhaps with the completion of primary treatments. Further research is needed to confirm these findings in a larger sample and investigate reasons for the decline seen.